Relatives as Members of the Treatment Team: What do We Know? Where Should We Go from Here?

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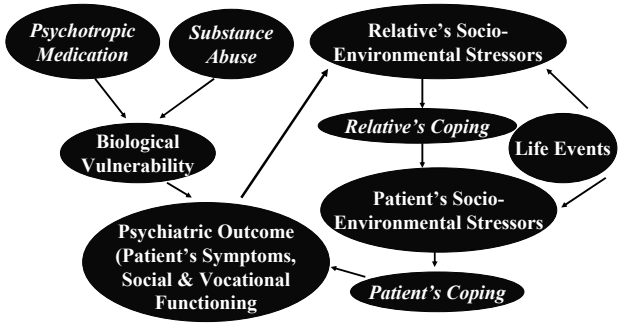
Presentation Organization

- Discussion of family issues pertaining to serious psychiatric illnesses
- Overview of intervention research
- Discussion of implementation difficulties
- Overview of novel online intervention
- Challenges in family intervention clinical applications

Some Provisos . . .

- Assumptions about the audience
- A note about language

The Stress-Vulnerability-Family Coping Skills Model of Adaptation to Psychiatric Disorders



Rationale for Family Intervention

- Deinstitutionalization Movement
- Mutual Interplay of Patient-Relative Stressors
- Reduced Funding for Services
- Distress in Relatives
- Expressed Emotion Research

Anderson et al.	Survival Skills Workshop and Individual Psychoed
Falloon et al.	Individual Behavioral Family Therapy
Leff & Vaughn	Home Engagement and Clinic Relative Groups
Mc Farlane	Multiple Family Groups
Tarrier et al.	Individual Structured Family Groups (behavioral vs. psychoed)

Characteristics of Effective Family Intervention Programs Which May Vary

- May be conducted individually or in a group
- Clinic or home-based
- Patient may be present or absent
- Some have a very behavioral emphasis (highly structured, behavioral rehearsals); others are more psychoeducational (more discussion, less structure)
- Long-term programs--9 to 24 months

Common Ingredients of Effective Family Intervention Programs

1. **Educate family about psychiatric illness and their management.**
2. **Show concern, sympathy, and empathy to family members who are coping with mental illness**
3. **Minimize interpretation—not psychodynamic or systemic**
4. **Avoid blaming the relatives or pathologizing their efforts to cope**
5. **Foster the development of all family members**

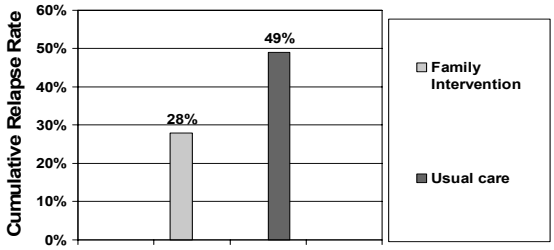
Common Ingredients of Effective Family Intervention Programs continued

6. **Enhance adherence to medication and decrease substance abuse and stress**
7. **Improve communication and problem solving skills in family members, either formally on informally**
8. **Provide treatment that is flexible and tailored to the individual needs of families**

Common Ingredients of Effective Family Intervention Programs continued

9. **Encourage family members to develop social supports outside their family network**
10. **Instill hope for the future**
11. **Take a long-term perspective**

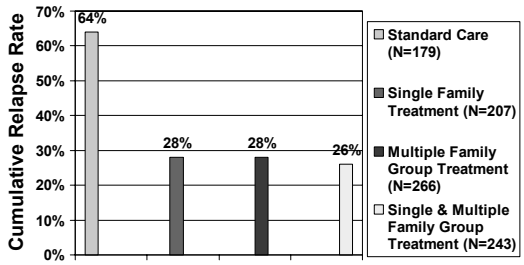
Mean Relapse Rates Over at Least 12 months-18 Studies Comparing Relapse Rates in Family Intervention to Usual Care (n=895)[1]



Pitchel-Walz G, Leucht S, Baumi J, Kissling W, Engel RR. Schizophr Bull. 2001

Although they are less studied, comparable results have been found in family interventions for bipolar illness, depression, and substance abuse

Combined Results of Family Intervention Programs on 2-year Cumulative Relapse Rates in Schizophrenia (11 Studies)



Advantages of Single and Multiple Family Formats of Family Interventions Programs

Single Family Format

- Easier to conduct outreach to families
- More suitable for addressing specific problem area, etc.
- More flexible
- Easier to engage family, especially early in illness

Multiple Family Format

- More economical (?)
- More social support provided by other families
- Less vulnerable to effects of staff turnover
- Easier to provide multiple sources of input to family member

Prevention of relapse is good; improving social functioning may be better. Some studies indicate family interventions result in improved social functioning, although data are limited

Some recent studies have had less robust positive findings -overall low relapse rates in all groups (Linzen et al; Hogarty et al; Potkin et al; Cochrane library review)

Possibilities

- Greater general information about psychiatric illness available to public
- Better tolerated and/or more effective medications
- Managed care and economic pressures reducing hospitalizations

How Do Family Interventions Achieve Their Benefits?

Possible hypotheses:

Data Equivocal and/or Negative

1. **Reduce expressed emotion (develop appropriate expectations)**
2. **Change communication patterns**
3. **Improve problem-solving skills**

Data Unavailable at this time

1. **Improve treatment compliance**
2. **Improve relative access to treatment team**
3. **Improve relatives' ability to recognize and act on prodromes**

PORT Recommendations

In 1992, the Agency for Health Care Policy and Research (AHCPR) and the National Institute of Mental Health established a Patient Outcomes Research Team (PORT) for schizophrenia at the University of Maryland School of Medicine and the Johns Hopkins University School of Public Health.

The prime objective of the PORT is to develop recommendations for the treatment of persons with schizophrenia based on a synthesis of the best scientific evidence.

Recommendation

Patients who have ongoing contact with their families should be offered a family psychosocial intervention that spans at least 9 months and provides a combination of education about the illness, family support, crisis intervention, and problem-solving skills training. Such interventions should also be offered to non- family caregivers.

Recommendation

Family intervention should not be restricted to patients whose families are identified as having high levels of "expressed emotion" (criticism, hostility, overinvolvement).

Recommendation

Family therapies based on the premise that family dysfunction is the etiology of the patient's schizophrenic disorder should *not* be used.

Unfortunately, family Interventions are not widely available

PORT Surveys, report by Young el al. (1998), and our recent Equip study at the VA GLAHS indicate that, at most, 40% of patients and relatives are offered family services--often closer to 25-30%--and these are rarely comprehensive family interventions

Why don't more agencies offer family based interventions?

- Provider Concerns
  - Time constraints/case load size
  - Theoretical orientation
  - Limited skills
  - Confidentiality issues
  - Reimbursement concerns

Why don't more agencies offer family based interventions?

- Patient Impediments
  - No desire for family involvement
  - No interest in family interventions
  - Too unstable to make regular appointments
  - Health issues

Why don't more agencies offer family based interventions?

- Relative Impediments
  - No desire for family involvement
  - No interest in family interventions
  - Logistical impediments (transportation, not traveling at night)
  - Other care-taking constraints
  - Illness
  - Scheduling
  - Stigma
  - Health Issues

Special Issues in Extrapolating Family Intervention Results to a VA Population

- Larger catchment area; transportation to sessions an issue
- Patients often became ill for the first time in service; have already left home
- Older patients
- Less involvement of parents in treatment; disproportional involvement of siblings and partners

New Innovations In Family Support

- More emphasis on engagement
- Family sponsorship (home based case management meetings with caregiver)
- On-line interventions
- Broadening intervention group (dual disorders patients, board and care-operators)
- Family to Family programs

Overview of Online Family Education to Promote Treatment Compliance in Schizophrenia

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What is our intervention?

Limited Access Website for Caregivers

1. Psychoeducational Written Materials
2. Facilitated Chat w/ mental health professionals (private access)
3. Streaming Videos
4. Resource Links
5. Message Board

In many ways, like a multiple family group on-line

Why not conduct a patient-based intervention?

- Limited access to computers
- Need for supervision? – Attentional and concentration deficits
- Clinical management an issue (e.g. crises)

Some Pilot Data on Feasibility

- Relatives of 32 veterans or community members dx schizophrenia or schizoaffective disorder
- Offered 12 months of internet intervention; pre-post design
- Primary outcome data collected at baseline, 12 & 18 months
- High rates of participation (over 70% for main Sunday night chat during intensive first six month phase)
- Low rates of rehospitalization (<15%)
- High rates of patient-reported med compliance, corroborated by relative (85% said they took meds as prescribed at least 75% of time)
- Positive attitude change by relative on FEIS

Six Things I Learned The Hard Way

1. **Family treatment can be effective, but it cannot compensate for too limited other services.**

2. **Relatives can be fragile too. Especially in light of community movement, many families have multiple members with serious psychiatric disorders. (2nd generation)**

3. **You can't assume anything about anybody, so you need to ask a lot of questions to be certain you understand the situation.**

4. **Provide frequent and compelling rationales for your interventions; try to get everyone on board.**

5. **Your flexibility helps overcome many obstacles.**

6. **Be gracious when you make a mistake.**

Summary

1. The emphasis on patients living in the community places more responsibility on relatives for participating in collaborative care
2. Family intervention programs can improve outcomes in serious psychiatric illnesses.
3. Family intervention programs are not widely available
4. We need to redouble our efforts to meet the needs of psychiatric patients and their loved ones through making rehabilitation programs, including family interventions, more available.